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ABSTRACT

A longitudinal study over a period of 12 months was conducted to assess the process of adjustment of adults to blindness and the factors that influence that adjustment. The visual impairment of the seven subjects took place from 5 days to 8 months prior to the study. Methods of data collection included observations in natural settings, ethnographic interviewing techniques, and two quantitative measures of social support and acceptance of disability: Linkowski's Acceptance of Disability Scale and Norbeck's Social Support Questionnaire. Three phases of the adjustment process were identified: pre-impact, impact, and learning to live with the impairment. Factors that influence adjustment were classified into: situations that informants find difficult, factors that help in adjusting, factors that do not help in adjusting, and coping strategies. (Author/DB)

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Adjustment of Adults to a Visual Impairment: Preliminary Findings

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Abstract

A longitudinal study over a period of 12 months was conducted to assess (a) the process of adjustment of adults to blindness and (b) the factors that influence that adjustment. The visual impairment of the seven participating adults took place from five days to eight months prior to inclusion in the study. There has been a need to investigate the process of becoming blind and the stages through which blind persons progress because previous studies concerned with adjustment to blindness are retrospective. Methods of data collection included observations in the natural settings, ethnographic interviewing techniques, and two quantitative measures of social support and acceptance of disability, namely Linkowski's Acceptance of Disability Scale (ADS) and Norbeck's Social Support Questionnaire (NSSQ). Three phases of the adjustment process are pre-impact, impact, and learning to live with the impairment. Factors that influence adjustment have been classified into situations that informants find difficult, factors that help and do not help in adjusting, and coping strategies.

Loss of vision produces serious physical, psychological, social, and economic consequences (Josephson, 1968; Lowenfeld, 1975) which necessitate a major adjustment to life (Franks, 1971). Demands for adjustment are placed on the visually impaired person at the time of the initial impact and in relation to the subsequent ongoing changes that occur because of the loss of vision. Most of the studies that have investigated adjustment to blindness are retrospective. These studies run the risk of losing data or having subjects distort data as they recall events. What was needed was a longitudinal approach to the study of adjustment to blindness. In this study, a longitudinal assessment of the adjustment of adults to blindness and the factors that influenced their adjustment was conducted.

Adjustment to Blindness

The initial reaction to a visual impairment consists of various stages or patterns of responses through which the person passes. This initial reaction to blindness has been equated to a grief syndrome in which persons grieve for their lost sight and go through a gradual process, not only of

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realization of the loss of vision, but also of the implications of that loss and the subsequent changes that will occur.

For most people, a steady pattern of adjustment appears to occur within the first year. The turning point in the process of recovery is that of reorganization and relearning (Hicks, 1978). Individuals integrate realistic limitations into their lifestyle and recognize the inherent dependence caused by their disability (Franks, 1971; Oehler-Giarratana, 1976).

In an investigation of the meaning of visual impairment to persons who lost their vision as adults, Allen (1985) also elicited several stages through which persons progressed as they learned to live with and adjust to their visual impairment. However, in his investigation, the data were retrospective in that persons recalled experiences of becoming and being visually impaired. Similarly, the majority of investigations on the reactions and adjustment to a visual impairment have been retrospective. That is, the process of becoming blind has not been investigated. Adjustment is an ongoing process. There is, however, a lack of knowledge about whether the needs that arise because of the vision loss and the responses to those needs change over time.

Factors Associated with Adjustment

Following these initial reactions to a visual impairment, the subsequent reactions and adjustment to the vision loss are associated with several physical, psychological, social, and environmental factors.

Physical Factors

Some of the physical factors that are associated with adjustment to a visual impairment include amount of residual vision, cause of the loss, and age of the person. Variations in sightedness have been found to correlate with a number of characteristics such as participation in the labor force (Feinman, 1978), social activity (Josephson, 1968), social function (Keegan, Ash, & Greenough, 1976), independence (Lukoff & Whiteman, 1970), and perceived happiness (Feinman, 1978). The cause of the loss of vision and the age of the person have been hypothesized to be related to the subsequent patterns of adjustment. There is contradictory evidence, however, as to whether visually impaired persons with greater acuity are better adjusted in terms of mobility and acceptance of vision loss and whether older or younger persons have more difficulty in adjustment.

Psychological Factors

The three psychological factors of (a) acceptance of visual loss, (b) previous personality and coping patterns, and (c) self-concept are associated with adjustment to a visual impairment. An important aspect

in adjustment to a visual impairment is the acceptance of the permanence of the loss or the loss of hope for restored vision (Pearlman, Adams, & Sloan, 1977). Research indicates that acceptance of blindness is associated with better psychological and social function (Keegan et al., 1976) and a willingness to acquire other skills and aids for blindness (Fitzgerald, 1970).

Social Factors

Social support and attitudes toward the blind and blindness are two social factors associated with adjustment of adults to a visual impairment. Personal writings of visually impaired persons attest to the contribution of the support of family and friends to their adjustment and independence. Also, in a large number of biographies of blind people, the attitudes of the sighted are singled out as the primary source of difficulties faced in adjustment. The idea that the blind have compensatory or magical abilities or are totally helpless were two commonly reported misconceptions. Research indicates, however, that the sighted population is far from unanimous in its attitude toward people and blindness.

Environment Factors

The four environmental factors of (a) legislation, (b) technology, (c) economy, and (d) organizations are associated with adjustment to a visual impairment. Legislation has been enacted expressly for the benefit of the visually impaired. Technological developments have created new opportunities for richer and more productive lives for blind people (Vaughan & Asbury, 1977). Devices have been created to assist in the achievement of independence in mobility and communication. Chances of achieving financial independence through employment are closely linked to the economic forces that impact on society as a whole. There is, however, higher unemployment among visually impaired populations than there is in the general working population. Also, employment opportunities for the visually impaired fall within a limited range. Organizations for the visually impaired do promote measures for the blind in terms of employment, rehabilitation, education, and legislation.

This study was designed to explore people's perceptions of adjustment as they go through the process of becoming and being visually impaired. The research questions that guided the inquiry were (a) What is the process of adjustment of adults to a visual impairment? and (b) What factors influence the adjustment of adults to a visual impairment?

Method

The methods of data collection were observations in the natural setting, elements of ethnographic interviewing techniques, and quantitative

measures of social support and acceptance of disability. Linkowski's Acceptance of Disability Scale (ADS) is a 50-item, six-point Likert-type scale based on the conceptualization of acceptance of disability as a process of value change. Norbeck's Social Support Questionnaire (NSSQ) is a self-administered questionnaire designed to measure multiple dimensions of perceived social support including functional components, network properties, and recent loss.

Subjects

A convenience sample of seven visually impaired persons (five women, two men) were the subjects of this study. Six subjects were referred to the investigator from the Canadian National Institute for the Blind (CNIB). The remaining subject was referred by nurses at a local hospital. The visual impairment of these persons took place from five days to eight months prior to inclusion in the study.

Procedure

The interviews with informants were of varying lengths of time and occurred over a period of 12 months. Two interviews were conducted in the first month of inclusion in the study. Following this, interviews were done on a monthly basis with telephone calls between these interviews to maintain ongoing contact with each informant. Each interview was tape-recorded and then transcribed.

The first interview began with the statement, "Tell me about your eye problems." Further questions and comments were generated and framed within the context of the interaction with the person and were directed toward eliciting the responses and reactions of persons to their impairment, the factors that influenced these responses and reactions, how the impairment affected their everyday life, and what changes in their life have been or will have to be made because of the impairment.

Observations were made of the subject's interactions with the investigator and significant others and their carrying out of any routine tasks that took place at the time of the interview. Observational notes were made as soon as possible after each interview with the informant.

The ADS and the NSSQ were administered three times during the data collection period. These times were at the initial interview, six months after the initial interview, and at the end of the data collection period. Adjustment, as an ongoing process, changes over time. Thus six months between testings was selected to allow for potential changes in adjustment and the factors associated with adjustment.

Data Analysis

Informants' responses and observational data were described and classified according to the core terms and conceptual categories that

emerged from a reading and abstraction of the data. The adjustment process and factors that influenced that process for each informant were described. Similar as well as divergent patterns were identified. The resulting model identifies the regularly recurring patterns and configurations of adjustment to visual impairment. Similarly, comparison of the factors that influence adjustment for each informant identified the common as well as divergent factors.

The relationship between social support, acceptance of disability, and adjustment that emerged from the analysis and from the two questionnaires was examined for congruence. Changes were noted from one testing to the next.

Results

Data collection is completed for this study and analysis has begun. The preliminary analysis of the data is presented in this paper. The configuration of adjustment may change when analysis is completed.

The Adjusting Process

The adjusting process appears to have three phases: pre-impact, impact, and learning to live with the impairment. In the pre-impact phase, informants were either not consciously aware of their vision loss or there was lack of recognition of the significance of the changes that occurred. There appears to be a gap between the time that the eye disease causes change in vision and the persons' recognition that he/she has an impairment. This may be related to perceptual ability. This gap does not occur in people who have become visually impaired very suddenly. However, these latter people do need to learn about their impairment. As one woman who woke up with no vision in her right eye said, "I don't know my limitations and what to expect; I still have to learn that."

Following awareness of their visual impairment, initial reactions to the impairment occurred. One woman stated, "It's like everything of value has been taken from you." Some words that people use to describe this period include shock, fright, uncertainty, surprise, depression, and uselessness. They wondered about the future and asked, "How will I cope?"

At some point after these initial reactions, people make the decision to learn to live with their impairment. Most of the people stated that there was no other choice: "You have to keep on going." When asked what leads to this decision, most subjects are unable to articulate the thinking that was occurring.

Learning to live with the impairment is an ongoing process. It does not move continuously forward. That is, people frequently reach a certain point in their adjustment and stay at that point for a period of time. What stimulates the next period of growth is still unclear. It may just be

time and experience and it may be that the factors that influence adjustment are operating.

Learning to live with the impairment is not easy. It is frequently seen as a battle or a fight. As one woman stated, almost every day she has to decide not to give in. There are ongoing reactions of frustration, annoyance, and impatience. For some there are good days and bad days. Good days are full of hope and bad days full of frustration. These ongoing reactions are not as overwhelming as the initial ones and do not last as long. This phase of adjustment can be a period of risk taking. The things that they felt they could not do (the can'ts) are readdressed, and attempts are made to learn strategies to turn these or some part of them into "cans."

Factors that Influence Adjustment

The data can be classified into several categories or factors that influence adjustment. These include things that informants find difficult, factors that help in adjusting, factors that do not help in adjusting, and coping strategies. Each is described briefly.

Situations that informants find difficult. Within this category are classified behaviors, tasks, or situations that informants state are the most difficult for them in adjusting to a visual impairment. The subcategories that emerge include (a) inability to carry out valued tasks, (b) inability to recognize friends and acquaintances, (c) explaining to others about their impairment, (d) asking for help, (e) carrying out activities of daily living, and (f) mobility.

Factors that help in adjusting. These are the factors that aid or facilitate learning to live with the impairment. Support is cited as the main factor that helps in adjustment. Support comes not only from family or friends but also from official agencies such as CNIB. This, in part, is because they have an opportunity to meet other blind people. Subjects state that it helps to have someone else who is visually impaired with whom to share experiences. Other things that aid adjustment include learning what they can still do, time, visual aids, information about their impairment, and their internal strength.

Factors that do not help in adjusting. These are the factors that informants state do not help in their adjustment to their impairment. These include lack of information, fluctuating vision, economic factors, comparison with previous abilities, pride, perceived unhelpful or negative behavior in people, other health problems, and the health care delivery system.

Coping strategies. Coping strategies refer to the actions, plans, or cognitive maneuvers that informants use to deal with the visual impairment itself and the emotions evoked by the situation. Informants reported using a combination of strategies. One particular strategy of

interest is comparison with others. Defining and evaluating others as "worse off" appears to be helpful for informants as a motivating factor for adjusting and as a means of achieving a sense of perspective about their impairment. Other strategies that subjects used included learning new ways, information seeking, search for meaning/attribution, establishing routines, taking each day at a time, and using previous coping strategies or experiences.

In summary, the multiple factors outlined in the categories influence each other and, in turn, influence the process of adjusting. As adjustment proceeds, the importance of each of the factors can also change. Explaining to others becomes easier, and the coping strategies are successful in helping the person learn new ways.

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